

Wojciech Bołoz

Human Ecology and Bioethics Centre, CSWU

Abandoning overzealous therapy as a realisation of rights of the dying

Abstract

The discussion on the right of the patient to "die with dignity" has been going on in the USA and Europe for 30 years. It focuses mostly on the following questions: 1. What is "death in dignity"? 2. Is man entitled to die in dignity, and if so, on what basis? 3. In what manner should we realise the right to die in dignity? The concept of "death with dignity" is conditioned by anthropological assumptions and tends to be understood as euthanasia or demise that maintains the personal and social integrity. The right to death is favoured by the principle of autonomy, but it is contradicted by the inviolable nature of the right to life, which can neither be renounced nor can anyone be deprived of it, even in the situation of a terminal disease.

The terminally ill and the dying do not cease to be humans; they still have their own personal dignity that every man is entitled to, and the human rights that originate from it and protect them in their particular situation. Therefore, such people have the right to be respected, to recognise their autonomy and to the truth. The rights of a dying person guarantee that they are treated with dignity when they have a terminal disease and that they can die with dignity. These rights demand that the dying are:

- treated as persons until death;
- provided with information concerning their health and part of the decision-making process;
- enable them to refuse the therapies, which prolong the agony.

Key words: Magisterium, overzealous therapy, the value of life, basic care, accompanying the dying, dignity, euthanasia

Adv. Pall. Med. 2008; 7: 93–100

Introduction


In 1972, the American Hospital Association edited the Declaration on Patients' Rights, which emphasises, among others, that the patient has a right to reject a suggested therapy and to be informed about its medical consequences [1]. The declaration initiated a discussion in America, which brought up a number of issues relating to patients' rights, including "the right to die in dignity". This discussion has never officially ended. It is periodically revived and includes more and more countries outside the USA. The discussion has recently reached Poland, where, similarly to other societies, we are looking for the answers to the following questions:

- what is "death with dignity"?
- is man entitled to die in dignity, and if so, on what basis?
- in what manner should we realise the right to die in dignity?

Ways to understand "death with dignity"

Dying is the last, integral stage of human life. Perceiving the death of man as part of life explains a lot, as it enables us to understand that death is subject to the same principles as life. As a consequence, the term "death with dignity" is strictly related to the idea of "life in dignity", as it expands

Address for correspondence: ks. prof. dr hab. Wojciech Bołoz
Human Ecology and Bioethics Centre, CSWU
e-mail: wboloz@onet.pl

 Advances in Palliative Medicine 2008, 7, 93–100
Copyright © 2008 Via Medica, ISSN 1898–3863

this concept. The dignity of dying and living is rooted in our humanity. Therefore, the way in which we understand it is conditioned by anthropological assumptions.

"Good death" as euthanasia

The term "euthanasia" was used for the first time around 300 BC in the comedy *Myrmex* by the Greek author Poseidippos. He used the following words: "Of all the things that man attempts to plead from the Gods, he cannot ask for anything better than a good death (euthanasia)" [2]. The term "euthanasia" was introduced to the modern language by Francis Bacon in 1605. In his work *"De dignitate et augmentis scientiarum"* (On dignity and the rise of science), he introduced the expression *"eutanasia exteriore — external euthanasia"*, by which he understood as, with medical assistance, a gentle and pleasant departure from life if the disease does not offer hope for recovery from the disease. According to his opinion, this type of euthanasia goes beyond the principle of assisting the dying person, and becomes a binding objective for doctors. The opposite of "external euthanasia", as Bacon puts it, is another type of euthanasia, which consists in a spiritual preparation to death [2].

Nowadays, the concept of euthanasia has become much more ambiguous. It is usually understood as a deliberate, direct, active or passive action which hastens the death of the sick, elderly and retarded, as well as an assisted suicide. The Encyclical *Evangelium Vitae* considers every "action or omission which of itself and by intention causes death with the purpose of eliminating all suffering" to be *per se* and by definition euthanasia, and later [3] reads that: "Euthanasia's terms of reference, therefore, are to be found in the intention of the will and in the methods used" [4]. This last remark about the meaning of intention in euthanasia has to be remembered, since, as it seems, only in some cases does it become the only criterion, which enables us to differentiate between passive euthanasia and futile therapy [5]. Each definition of euthanasia contains the following elements:

- a person, whose death is hastened;
- another person, who participates in the hastening of death;
- the motivation to care for or the desire to relieve the sick person from suffering.

The difference between active and passive euthanasia does not alter those elements, but the methods applied. There is, however, a very significant difference between voluntary and non-voluntary euthanasia. In the case of voluntary euthana-

sia, we can at least assume the patient's autonomy and his consent for such an act of murder, but the other type is deprived of even those essential conditions, required in all types of medical interventions concerning human health and life [6]. Such actions cannot, in any form, comply with the requirements of human right, particularly the right to live.

The personalistic concept of "death with dignity"

Personalistic orientated circles, which oppose the legalization of euthanasia, emphasise, that "death with dignity" means natural death, resulting from a terminal disease or lack of biological ability of the patient's organism to continue life due to ageing, without applying artificial means to prolong life or hasten death. Only such a death does not infringe the fundamental right to live. Dying with dignity also means retaining personal integrity as much as possible, i.e. the fundamental features a person is entitled to: consciousness and subjectivity, which in this stage of life are translated into participation of the patient in the therapeutic process. One of key elements of dying with dignity is the possibility to continue basic social roles and relations, thus maintaining contact with relatives (family and friends), which makes it possible for the patient expecting death to stay at home, instead of in a hospice or hospital. Last but not least, dying with dignity means the lack of pain and other negative symptoms, which may distress and distract the dying person, and make their relations with the environment much more complicated.

This interpretation of the right to die with dignity was also supported by the Catholic Church in the words: "The right to life is specified in the terminally ill person as a right to die in total serenity, with human and Christian dignity. This cannot be interpreted as the power to kill oneself or to give this power to others, but to experience dying in a human and Christian way and not flee from it at any cost" [7]. Human dignity demands that "man is able to end his life maintaining, as much as possible, the integrity of personality and relationships, which connect them with the surrounding, particularly the family" [8].

The right to death with dignity?

Since the concept of "death with dignity", similarly to the idea of "life with dignity" is conditioned by accepted anthropological assumptions; therefore, the right to death with dignity has various interpretations. The utilitarian circles and those that prefer

relativistic ethics interpret the right to death with dignity as the right of the patient to euthanasia. According to those circles, the basis for such a right is the autonomy of man, which enables them to make decisions about themselves, including their life. Supporters of personalistic ethics and the principle of human dignity protected by human rights believe that the consent to euthanasia of terminally ill patients in the name of their autonomy is to be regarded as abuse. There are no sufficient grounds to agree that patients may only renounce their right to life in the situation of a terminal disease, in the name of patients' autonomy, and not to expand this principle to include all people in all kinds of situations [6]. "If we truly believe in self-determination, then a competent person should have the right to be killed by a doctor for any reason they may see fit. If we believe in the freedom from suffering, then refusing them such competence seems cruel and fickle" [9]. Consequently, either the principle of autonomy, which authorises the renouncement to the right to life, should be expanded to include all cases, or it should not exist at all. Limiting this principle solely to the terminally ill leads to its instrumentalisation. People not only have right, but also the obligation, to retain their own rights and respect the rights of other people in all situations, not confined to those which favour us or others. Human rights and the obligation to respect them cannot be separated [10]. If we do not consider the right to life as inviolable, which means that it cannot be renounced nor can anyone be deprived of it, then there are no grounds to make an exception in the situation of a terminal disease.

Basic rights of dying persons

The discussions concerning dying with dignity include many references to religious, ethical and social arguments, which speak against the legalisation of euthanasia and in favour of the consent to abandon overzealous therapy. However, it seems that only to a little extent do the opponents of euthanasia make reference to the most universal moral criterion of the modern world, which is the human right based on the conviction formulated in the Universal Declaration of Human Rights (art. 1): "All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood". The dignity of man and the rights that originate from it are the only universal and commonly accepted moral principle in the modern and pluralistic world, accepted by people of all

worldviews, including the Catholic Church. The Catholic interpretation of human rights and its substantiation has been presented in its entirety in the encyclical *Pacem in terris*, by Pope John XXIII. He wrote, among others, that "any well-regulated and productive association of men in society demands the acceptance of one fundamental principle: that each individual man is truly a person. His is of a nature that is endowed with intelligence and free will. As such, he has rights and duties, which together flow as a direct consequence from his nature" [11]. It is not without its significance, that the united Europe has perceived human rights as the fundamental elements of European identity for over thirty years [12].

Human rights result from the structure of this identity, thus their number is limited. The basis for human rights to be binding and inviolable is human dignity, understood as a specific value and eminence of each representative of the *Homo sapiens* species, conditioned by the uniqueness of man, which sets them apart among all creatures living on Earth. It is universally accepted that there are three generations of human rights, which were gradually brought to attention of societies: political and civil rights which protect each person against the dictatorship of the individual, and the democratic majority (freedom rights); economic and social rights, which protect against the discrimination on unequal treatment, and solidarity rights which guarantee equal access to development [13]. We can also talk about existential human rights, that is the application and specification of the rights included in the Universal Declaration of Human Rights to a specific existential situation, which demands special protection. We can, therefore, refer to the Convention on the Rights of the Child, Charter of the Rights of the Family, Charter of Patient's Rights and Charter of the Right of Dying Person.

The terminally ill and the dying do not cease to be human; they still have their own personal dignity that every man is entitled to, and the human rights that originate from it and protect them in their particular situation. Therefore, such people have the right to be respected, their autonomy to be recognised and to the truth. In this context, the rights of the dying appear to be the rights which guarantee human dignity until death [14].

The right to receive proper treatment until death

The process of ageing can be divided into three aspects: biological (impairment and loss of cell and tissue functions), psychical (reduction and loss of

psychical functions), and social (gradual withdrawal from social roles). The tempo and way of ageing are conditioned endogenously (the genetic code) and they also depend on the lifestyle and psychical attitude of a particular person, in the periods which precede ageing and during the process of ageing. Human and natural environment, in which people live, also have their effect. The development of Personalism in the 20th century made us aware that the reductionism, which confines humanity only to biological functions, it to be avoided. A person is to be seen as a spiritual and bodily composition that has a personal status and the right to live, regardless of the quality of its vital functions. The subject of the right to life is "the human being (...), in every phase of development, from conception until natural death; and in every condition, whether healthy or sick, whole or handicapped, rich or poor" [15].

In our times of relativism, there is a growing tendency to grant the right of life only to those human beings, who are endowed with a sufficiently high quality of life and function on a proper individual and social level. In relation to human rights, and particularly the right to life, two fundamental principles apply: no one can arbitrarily grant or refuse human rights to any human being; they also cannot be refused such rights on the account of having or not having certain features. Who would therefore have the right to define the quality of life in the terminally ill and classify them into those who still have and who have lost the right to life?

Peter Singer, an Australian ethicist, is a well-known opponent of unconditional granting the right to life to every human being. He makes a difference between a human being, and a person. According to his view, a person is a living being, empowered with the following four features:

- it is a conscious and autonomous being;
- it has a will to last and enjoys certain experiences;
- it has the ability to make physical, social and intellectual contacts with other beings;
- it has relatives, who would mourn after his or her death [16].

This definition enables Singer to recognise a foetus, a newborn human child and a person with dementia as members of the human species, but he refuses them a personal status. This perspective leads him, as a consequence, to the conviction that a terminally ill person, deprived of autonomy and consciousness, deserves only euthanasia. Because of the fact that Mr Singer has found many supporters, it is very important for the terminally ill and the dying

to guarantee them the right to personal status until death.

The right to information concerning One's own health and participation in the decision-making

Modern medical ethics and medical laws highlight the right of the patient to be informed about their health condition. With this right in mind, we cannot forget that the process of conveying information must be performed in a kindly manner. The manner in which the information is conveyed to the patient is of crucial importance. The Anglo-Saxon tradition stresses the autonomy of every human being and the right of a patient to be informed about the whole truth, regardless of the prognosis. The European tradition requires taking into account the situation of the patient. According to the binding Medical Code of Ethics, "a doctor may refrain from informing the patient about this health condition or treatment, if the patient expresses such will" (art. 16). "In the event of an unfavourable prognosis, the doctor should inform the patient with tact and caution. The patient may not be informed about diagnosis and unfavourable prognosis only in the event that the doctor is deeply convinced that revealing such information would inflict great suffering upon the patient, or bring other negative results to health. However, he is obliged to convey the full information upon an explicit request of the patient" (art. 17). The Anglo-Saxon and European way of conveying information to the patient is sometimes supplemented with a third form, which consists in doctors assisting patients in a gradual revealing of the truth about their condition by themselves.

While every patient has the right to be informed about their health condition, then, consequently, all people suffering from incurable diseases are entitled to this right as well. The approaching death is a too significantly personal event to keep it secret from the sick person. A dying person has not only rights, but also obligations. "For every person the proximity of death bears a responsibility to fulfil certain duties, relating to the relationship with their family, sorting out all potential professional affairs, updating the accounts and debts, etc." [8].

Apart from the existing difficulties connected with communication with the terminally ill, they cannot be refused the right to be informed about their condition. There are numerous reasons to support this point of view:

- respect for another human being demands to deliver to him or her data, which would make him or her aware of their health condition;
- sooner or later, the patient will learn the truth, but they will be alone with it, deprived of professional help;
- cooperation of the patient in the terminal stage of the disease is of crucial importance, and a well-informed patient may become more motivated;
- patients should have the opportunity to organise their family, legal and religious matters;
- patients will feel safer, if they can be open towards the environment in this difficult time of dying;
- concealing the truth reduces the authority and confidence towards the doctor and his associates [17].

“The perspective of death complicates and dramatises the conveying of information, but it does not absolve one from the responsibility of conveying it. The communication between the dying and those who assist them must not be based on pretending. The dying do not deserve such a demeanour and it does not contribute to the humanisation of death” [7].

The patient also requires comprehensive information about their condition, so that they can participate in the decision-making concerning the applied therapy. Medical laws, codes and declaration concerning medical ethics demand this principle to be observed. According to the so-called European Bioethical Convention, every medical intervention must be based on the consent of the person interested. “An intervention in the health field may only be carried out after the person concerned has given free and informed consent to it. This person shall beforehand be given appropriate information as to the purpose and nature of the intervention as well as on its consequences and risks. The person concerned may freely withdraw consent at any time” [18].

The realisation of the patient's right to be informed about their condition, and the right to be part of the decision-making about applied therapies, has significant consequences in the terminal disease as well. Therefore, if the terminally ill patients have not yet settled their affairs, one can refrain from analgesia leading to restricting consciousness of the patient, so as to give them time to fulfil their obligations. However, if the patient refuses to do that and insists on taking painkillers, the doctor is obliged to satisfy that will. Such con-

duct is substantiated by the conviction that fulfilling those obligations by the patient is left solely to his discretion. Even the patients with full mental capacity may refuse to satisfy the obligations that rest with them.

The right to refuse a therapy that prolongs the process of dying

Modern medicine has the unique means of healing and prolonging human life. Such therapies consume vast amounts of financial assets, and they are often connected with uncomfortable medical interventions, which do not bring the expected improvement of patients' condition. This is the reason for bringing up a significant issue of how long the patient, their family and society are obliged to take such therapies. It is difficult to determine the scope of obligations for the patient, doctor or relatives, in each separate case of any disease. In order to facilitate such decision, the concept of ordinary and extraordinary medical means was developed in the past.

Ordinary means of treatment are such means which:

- is financially accessible to the majority of people living in a given country;
- does not induce excessive and prolonged suffering of the patient;
- has the potential of recovery.

The extraordinary means are those which:

- are very expensive, *i.e.* are beyond the financial capability of the patient, family and the regular services of the social health care;
- may result in severe and negative organic or psychological effects (e.g. brain surgery may lead to permanent disorders of psychological functions);
- offers little hope for recovery. The use of the latter is left to the patient's sole discretion. However, nobody is morally obliged to use them [19].

Today, we tend to talk about proportionate and disproportionate medical measures, which should be implemented to restore health and save life, or abandoned. This difference is conditioned by specific cases, and the criteria for such differentiation are both objective and subjective. Objective criteria include: the nature of applied measures, their financial cost and the consequences resulting from the principle of justice. Subjective criteria include: the necessity to avoid anxiety and dread, distress, discomfort, and the psychological shock related to the implementation of those measures. The fundamental criterion of differentiation is the proportion

between means and purpose that one wants to achieve with the means implemented.

Discontinuing medical procedures that are burdensome, dangerous, extraordinary, or disproportionate to the expected outcome can be legitimate. This is the refusal of the so-called "overzealous therapy", which consists in the use of extraordinary medical procedures (technical appliances and pharmacological means), in order to artificially sustain vital functions of the patient suffering from a terminal disease and delay the moment of death. Overzealous therapy is medically ineffective, prolongs agony in a limited way (sometimes up to a few months), and results in extremely high financial costs and disproportionate personal costs (suffering and limited functioning) for the patient and/or their family. Overzealous therapy does not include basic nursing services (feeding and hydrating, alleviating pain and other symptoms). The decision to abandon overzealous therapy is made by free and well-informed patients themselves, after having been acquainted with a medically substantiated opinion of a competent doctor, and according to his knowledge and conscience.

The concept of overzealous therapy and the possibility to abandon it is found in the documents of the Catholic Church. In the situation when "when death is clearly imminent and inevitable, one can in conscience refuse forms of treatment that would only secure a precarious and burdensome prolongation of life, so long as the normal care due to the sick person in similar cases is not interrupted. (...) To forego extraordinary or disproportionate means is not the equivalent of suicide or euthanasia; it rather expresses acceptance of the human condition in the face of death" [4]. The decisions should be made by the patient if he is competent and able or, if not, by those legally entitled to act for the patient, whose reasonable will and legitimate interests must always be respected [20]. In this context, let us refer to the letter of Cardinal Villot to the International Federation of Catholic Medical Associations: "It must be emphasised that it is the sacred character of life which forbids a physician to kill and makes it a duty for him at the same time to use every resource of his art to fight against death. This does not, however, mean that a physician is under any obligation to use all and every one of the life-maintaining techniques offered to him by the indefatigable creativity of science. Would it not be a useless torture, in many cases, to impose vegetative reanimation during the last phase of an incurable disease?" [8].

Although the concept of overzealous therapy and the possibility of abandoning it have been univer-

sally accepted in the medical ethics of today, these issues still remain controversial and many questions relating to overzealous therapy has not found clear answers [21]. Those questions include: Does abandoning overzealous therapy mean refraining from it, or withdrawing from the therapy already implemented as well? Can a doctor refrain from overzealous therapy against the will of the patient? What does it mean to "refrain from overzealous therapy" in terminally ill patients suffering from heart, renal or lung failure? Let us hope that these questions will be answered in the future.

Conditions of abandoning overzealous therapy

The definition of overzealous therapy, worked out by the participants of the II Expert Seminar, as part of the project Boundaries of medical therapies, that took place on 29th June 2008, is the following: "Overzealous therapy is the application of medical procedures with the goal of supporting vital functions in a terminally ill person that results in prolonged dying, and is associated with excessive suffering and/or with violation of the patient's dignity. Overzealous therapy does not include basic nursing, control of pain and of other symptoms or feeding and fluid administration, as long as these actions are beneficial to the dying person" [22].

Abandoning futile therapy requires respecting the following principles:

1. Human life is treated as a value not conditioned by health condition, quality of this life, autonomy of the patient and their ability to think and express their will.
2. The difference between a life worthy and unworthy of its continuation is arbitrary, since the dignity of the human being is not conditioned by the biological status of the organism.
3. Abandoning overzealous therapy may consist in refusing to implement it or withdrawing from the procedures already implemented.
4. The only justification of abandoning overzealous therapy is providing the dying person with a natural death with dignity, and not providing savings in the health care system.
5. The goal of abandoning overzealous therapy is not the shortening the life of a patient, but not prolonging the agony and delaying what is inevitable.
6. The extraordinary and ineffective character of medical means is objective, conditioned by the current level of medicine development and the economic situation of a country.

7. Disproportionate personal costs of overzealous therapy are conditioned by the personality of the patient, their sensitivity and resistance to pain and suffering.
8. Abandoning overzealous therapy is an autonomous decision of the patient, who is well informed about their condition and impending death.
9. If the patient is unable to express their will personally, the family may convey such information to the doctor, according to previously expressed attitude of the patient.
10. A doctor's decision to refrain from implementing or abandon overzealous therapy may be taken after the patient has reached a critical state, predicted in the scenario of death for a given type of disease.
11. A doctor's decision to refrain from implementing or abandon overzealous therapy should be in accordance with the binding legal system.
12. The will of the patient, expressed in the "Living Will", informs the doctor about their wish. The doctor makes a decision, according to his or her knowledge and conscience.
13. Hydrating and feeding is considered to be a basic nursing service. Abandoning such services may be caused only by the objective well-being of the patient, when their continuation has the hallmark of therapeutic persistency.

References

1. Jonsen A.R. *The Birth of Bioethics*. Oxford University Press, Oxford, New York 1999.
2. Benze Höfer U. *Der gute Tod? Euthanasie und Sterbehilfe in Geschichte und Gegenwart*. Verlag C.H. Beck. München 1999.
3. John Paul II. *Encyclical Evangelium Vita (The Gospel of Life)*. Libreria Editrice, Vaticana 1995.
4. Congregation for the Doctrine of the Faith, Declaration on Euthanasia *Iura et Bona* (5 May 1980), II: AAS 72 (1980), 546.
5. Biesaga T. *Elementy etyki lekarskiej*. Medycyna Praktyczna, Kraków 2006.
6. McConnell T. *Inalienable Rights. The Limits in Medicine and the Law*. Oxford University Press, Oxford, New York 2000.
7. Pontifical Council for Health Pastoral Care. *The Charter for Health Care Workers*. Vatican City 1995.
8. Pontifical Council Cor Unum. *Some Ethical Questions Relating to the Gravely Ill and the Dying*. Vatican 1981.
9. Callahan D. *When Self-Determination Runs Amok*. Hastings Center Report 1992; 22: 52-55.
10. Hill Th. *Autonomy and Self-Respect*. Cambridge University Press, New York 1991.
11. John XXIII. *Encyclical Pacem in terris (Pacem in terris)*. Vatican 1963.
12. Chabot J.L. *Unia Europejska i prawa człowieka*. Społeczeństwo 2001; 10, 1: 27-43.
13. M. Freemann M., *Prawa człowieka*, Wydawnictwo Sic, Warszawa 2007.
14. Bołoz W. *Bioetyka i prawa człowieka*. Wydawnictwo UKSW, Warszawa 2007.
15. John Paul II. *Christifideles laici (The Lay Members)*. Vatican 1988.
16. Singer P. *O życiu i śmierci. Upadek etyki tradycyjnej*. PIW, Warszawa 1994.
17. Schweidtmann W. *Sterbebegleitung. Menschliche Nähe am Krankenbett*. Kreuz Verlag, Zürich 1991.
18. Council of Europe. *Convention for Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Biomedicine: Convention of Human Rights and Biomedicine*. Oviedo 1997.
19. Bołoz W. *Życie w ludzkich rękach. Podstawowe zagadnienia bioetyczne*. Warszawa 1997.
20. *Catechism of The Catholic Church*. Published by Doubleday, New York 1995.
21. Aszyk P. *Granice leczenia. Etyczny problem odstąpienia od interwencji medycznych*. Rhetos, Warszawa 2006.
22. *The definition of Overzealous Therapy. The consensus of the Polish Working Group on End-of-Life Ethics*. *Advances. Adv. Pall. Med.* 2008; 7: 91-92.